

TESTIMONY
Before
The United States House of Representatives
Committee on Energy and Commerce
Subcommittee on Health

Hearing on
Answering the Call: Medical Monitoring and Treatment of 9/11
Washington, DC
September 18, 2007

Presented by
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Honorable Chairman Pallone and other members of the Subcommittee on Health. I greatly appreciate the opportunity to appear before you at this hearing.

I am James Melius, an occupational health physician and epidemiologist, who currently works as Administrator for the New York State Laborers' Health and Safety Trust Fund, a labor-management organization focusing on health and safety issues for union construction laborers in New York State. During my career, I spent over seven years working for the National Institute for Occupational Safety and Health (NIOSH) where I directed groups conducting epidemiological and medical studies. After that, I worked for seven years for the New York State Department of Health where, among other duties, I directed the development of a network of occupational health clinics around the state. I currently serve on the federal Advisory Board on Radiation and Worker Health which oversees part of the federal compensation program for former Department of Energy nuclear weapons production workers.

I have been involved in health issues for World Trade Center responders since shortly after September 11th. Over 3,000 of our union members were involved in response and clean-up activities at the site. One of my staff spent nearly every day at the site for the first few months helping to coordinate health and safety issues for our members who were working there. When the initial concerns were raised about potential health problems among responders at the site, I became involved in ensuring that our members participated in the various medical and mental health services that were being offered. For the past three years, I have served as the chair of the Steering Committee for the World Trade Center Medical Monitoring and Treatment Program. This committee includes representatives of responder groups and the involved medical centers (including the NYC Fire Department) who meet monthly to oversee the program and to ensure that the program is providing the necessary services to the many people in need of medical follow-up and treatment. I also serve as co-chair of the Labor Advisory Committee for the WTC Registry operated by the New York City Department of Health. These activities provide me with a good overview of the benefits of the current programs and

the difficulties encountered by responders seeking to address their medical problems and other needs.

I believe that other physicians involved in the medical monitoring and treatment program for World Trade Center responders have already presented the medical findings from their respective medical program for these responders. The pulmonary disease and other health problems among both fire fighters and other responders are quite striking and quite worrisome. All of the medical programs have done an outstanding job in establishing their respective monitoring programs and in providing high quality medical examinations for many thousands of rescue workers and responders. These programs also recognized the problems that many of their participants were having paying for medical care for the conditions diagnosed in the medical monitoring programs and have made efforts to help the participants in obtaining necessary assistance. Given the focus of these hearings, I believe that it may be helpful to examine the reasons why so many of the participants need assistance for paying for their medical treatment.

HEALTH INSURANCE COVERAGE

The people who worked in the initial response to the September 11th disaster and the later recovery activities represented many different types of workers. On the public safety side, there were fire fighters, police, and emergency medical services workers. The response and recovery activities also included construction trades workers, utility workers, sanitation workers, transit workers, cleaning workers, and NYC municipal workers from many agencies. Many other people just volunteered to work at the site especially in the first few days after September 11th. Despite the diversity of backgrounds and job duties, these different groups are showing very similar patterns of illness. The pulmonary changes found in fire fighters have also been demonstrated in the rescue and recovery workers being monitored in the Mount Sinai medical program. Most recently, an independent study conducted by medical researchers at Penn State University of NYC police officers responding to the WTC disaster reported similar respiratory findings among the group that they examined. The other types of medical and mental

health problems documented among WTC responders also appear to be similar across all groups of responders.

However, given the diversity of this workforce, it is not surprising that their health insurance coverage might be quite variable. I will provide a general overview.

All city workers are covered through the city's general health insurance plan which provides basic coverage including retirement coverage for long time workers. However, pharmaceutical coverage is provided through a different plan administered through each separate union. Construction trade workers are usually covered through their labor-management health insurance fund which provides basic health insurance coverage and some pharmaceutical coverage. The pharmaceutical coverage is often quite limited with high deductibles and co-pays. These health plans require that the participant work a substantial number of days each quarter or year in order to maintain eligibility. An ill construction worker can easily lose their coverage by missing too many work days. Utility workers have general medical coverage including some pharmaceutical benefits. Cleaning workers (people who cleaned the residential and commercial buildings around the WTC) often worked for contractors who offered no health benefits at all. The majority of the people in the Mt. Sinai treatment program up to now have had no health insurance coverage or very limited coverage.

All health insurance plans exclude coverage for work-related injuries and illnesses. Even Medicare has an active program to identify and recover payments for work-related services. While it is recognized that there may be uncertainty about whether a condition being diagnosed is work-related or not, this consideration could easily lead to the denial of health insurance coverage for many people with WTC-related health conditions. New York State does have in place mechanisms for health insurance providers to be reimbursed for medical expense payments incurred for conditions that are ultimately determined to be eligible for workers' compensation coverage. However, these mechanisms are administratively complicated and do not necessarily prevent the health insurer from denying reimbursement for WTC-related health expense.

Another problem with health insurance is the limitations on coverage of many of the health insurance plans that cover the participants. This is especially critical for pharmaceutical coverage. Treatment for many of the WTC-related conditions (asthma, mental health problems, etc.) requires substantial medication costs. These costs commonly range from \$5000 to nearly \$15,000 per year for participants. Many of the plans covering WTC participants have high deductibles or co-pays. Co-pays and deductibles can easily cost the participants with high medication costs several thousand dollars per year. These costs can severely strain the finances of a person with a moderate income especially if they have other health care costs and are missing significant time from their work due to illness. For those without any health insurance, the financial impact is even greater. Another potential problem is that many of these insurance programs have lifetime caps for each participant. Although these caps seem high (\$500,000 to \$1 million or more), they can easily be exceeded with a long term serious illness.

The medical and pharmaceutical costs for WTC-responders have also severely strained the health insurance plans for many of the responder groups, especially those providing pharmaceutical coverage. These funds are already stressed by the rapidly rising costs of health care. Those plans with a significant number of members who worked at the WTC response and clean-up have found that the overall medical and pharmaceutical costs for their plans have significantly increased due to the large number of participants with WTC-related medical costs. This has even led some to consider cutting back on their benefits for all members in order to absorb the costs for the WTC group.

WORKERS' COMPENSATION COVERAGE

One alternative to health insurance coverage for WTC-related conditions is workers' compensation insurance. Workers' compensation is supposed to be a no fault insurance system to provide workers who are injured or become ill due to job-related factors with compensation for their wage loss as well as full coverage for the medical costs associated with the monitoring and treatment of their condition.

Similar to health insurance, the WTC program participants are covered by a variety of state, federal, and local programs with different eligibility requirements, benefits, and other provisions. Most private and city workers are covered under the New York State Workers' Compensation system. New York City is self insured while most of the private employers obtain coverage through an outside insurance company. Uniformed services workers are, for the most part, not covered by the New York State Workers' Compensation system but rather have a line of duty disability retirement system managed by New York City. A fire fighter, police officer, or other uniformed worker who can no longer perform their duties because of an injury or illness incurred while on duty can apply for a disability retirement which allows them to leave with significant retirement benefits. However, should a work-related illness first become apparent after retirement, no additional benefits (including medical care) are provided, and the medical benefits for even a recognized line of duty medical problem end when the person retires. Federal workers are covered under the compensation program for federal workers. Coverage for workers who came from out of state will depend on their employment arrangements with their private employer or agency. However, volunteers from New York or from out of state are all covered under a special program established by the New York Workers Compensation Board after 9/11.

The major difficulty with these compensation systems is the long delays in obtaining coverage. For example, the NYS Workers' Compensation system is very bureaucratic. The insurer may challenge every step of the compensation process including even diagnostic medical testing. This challenge usually requires a hearing before a Workers'

Compensation Board (WCB) administrative judge to evaluate the case, and this hearing may often be delayed for months. Even once the case is established, the insurer can still challenge treatments recommended for that individual even for a medication that the individual may have been taking for many months for a chronic work-related condition. Thus, it may be many years before the case of a person with a WTC-related condition is fully recognized and adjudicated by the compensation system. Meanwhile, the claimant may not be receiving any medical or compensation benefits or may have had their benefits disrupted many times.

In order to alleviate some of the problems for WTC claimants, last year New York State implemented some new programs that were designed to improve coverage for WTC responders by providing medical coverage and salary compensation for responders while their WCB cases were being evaluated. However, these provisions must be initiated by the insurer carrier, and there is uncertainty as to who would be responsible for reimbursing these costs if the claims are ultimately denied. To date, these provisions do not appear to be widely used. There was also legislation passed last year that allows more New York City workers to obtain disability retirement benefits for WTC-related conditions. Currently, there is an advisory task force in place that is examining how best to implement this legislation. Finally, there was a bill passed allowing people who worked at the WTC site to register for Workers' Compensation benefits. Potential claimants were given a year to submit a registration form to the Board that makes them eligible to apply for benefits should they later develop a WTC-related health condition. Prior to that, claimants who later developed a WTC-related medical condition were not eligible to file claims because they were judged to have missed the filing deadline required by law. In addition, New York State has just passed broad workers' compensation reform legislation that makes many changes in the current system. Once implemented, this legislation could help to alleviate some of the delays in the current system. However, it will be some time before all of these changes assist WTC claimants. Meanwhile, claimants continue to face long delays and many hurdles in obtaining workers' compensation coverage for any conditions resulting from their WTC exposures.

It is not clear that the recent changes in the system will adequately address these problems.

I would also add that depending on workers' compensation and disability retirement systems to cover the medical costs for the monitoring and treatment program places the financial burden on the employers and insurance companies. New York City is self insured and thus would pay directly for all claims. The private employers involved will also have greater costs either by directly paying for claims if they are self insured or through higher premiums due to an increase in their experience rating.

COMPREHENSIVE SOLUTION

A comprehensive solution is needed to address the health needs of the 9/11 rescue and recovery workers. We cannot rely on a fragmented system utilizing private philanthropy, health insurance, line of duty disability retirement, and workers' compensation to support the necessary medical monitoring and treatment for the thousands of people whose health may have been impacted by their WTC exposures. This fragmented approach will inevitably leave many of the ill and disabled rescue and recovery workers without needed medical treatment and will only worsen their health conditions. The delays and uncertainty about payments would discourage many of the ill rescue and recovery workers from seeking necessary care and discourage medical institutions from providing that care.

This is a critical time for the federally funded treatment programs. Their funding will soon run out, and federal officials are already proposing sending letters informing the participants that they must seek alternative arrangements for their care. Attempting to provide this care through some sort of voucher system as is currently being considered by the Department of Health and Human Services would also be disruptive. Discontinuing or disrupting this high quality, coordinated medical treatment would only exacerbate the health consequences of the 9/11 disaster. Most of the participants in the monitoring and treatment program have medical conditions (asthma, mental health problems, etc.) that

should be responsive to medication and other treatments. Hopefully, many of these people will gradually recover and not become disabled due to their WTC-related medical conditions. To the extent, that we can prevent worsening of the medical conditions and prevent many of these people from becoming too disabled to work, we can not only help these individuals, but we can also lower the long term costs of providing care and assistance to this population.

We need federal legislation that accomplishes the following:

1. Provides long term medical monitoring program for all WTC responders and other workers exposed in the aftermath of September 11, 2007
2. Supports long term medical treatment for those participants who have developed WTC-related medical conditions at no cost to the participants. This program should cover WTC-related medical conditions that are currently recognized as well as those which might emerge in the future.
3. Provides that monitoring and treatment at Medical Centers of Excellence that have the expertise and experience to provide high quality medical care.
4. Extends that high quality medical care to WTC responders from throughout the United States
5. Provides for the collection and analysis of these medical data in order to track the health of the participants and to detect emerging disease patterns.
6. Establishes a medical monitoring and treatment program for residents, students, workers, and other people who were exposed to WTC contaminants in the aftermath to the September 11 attacks.
7. Provides for appropriate compensation for those who have become disabled from their WTC-related illnesses.

8. Provides administrative mechanisms that provides prompt and timely determinations and allows the proper oversight and management of the program.
9. Provides for meaningful input and participation from representatives of the affected groups in the development and management of the program.

The legislation just introduced by Representatives Maloney, Nadler, Fossella, and others addresses all of those goals and provides the comprehensive framework needed to address the serious medical problems being experienced by thousands of people in the aftermath to the September 11 terrorist attacks. Too often in the past, we have neglected to properly monitor the health of groups exposed in extraordinary situations only to later spend millions of dollars trying to determine the extent to which their health has been impacted. Agent Orange exposure in Vietnam and the current compensation program for nuclear weapons workers are only two examples of this problem. We have left those people to suffer, often without proper medical care and facing financial hardship due to their illnesses. We should learn the lessons from these past mistakes and make sure that we provide comprehensive medical monitoring, treatment, and compensation for those potentially impacted by the WTC disaster.

I would strongly urge you to take immediate steps to ensure that there is adequate federal funding for the current medical monitoring and treatment programs and to open up these programs or similar programs to the affected residents and to other affected workers. I would also urge you to support the Maloney-Nadler-Fossella legislation to provide a comprehensive approach to give WTC workers and residents access to long term medical monitoring and treatment for their WTC-related medical conditions and compensation for their losses.

I would be glad to answer any questions.